



Martin Marion

# Living More Independently — It Gives Them Hope

by Holly Hales Marion

**U**p until 1959, if you had a physically or mentally disabled child in Charlotte you had two options. You could keep the child at home, dependent on a family member for care. Or you could send the child to an institution, more than likely a state or private mental institution or a nursing or rest home.

In 1959, a group of parents of mentally retarded children got together to seek other alternatives in the Charlotte community. They expressed a strong desire to keep their children out of institutions. But at the same time, if their disabled children were to continue to live at home, they needed qualified day care and training in skills necessary for independent living. These parents believed their children had the same right as any child to learn to take care of themselves for the inevitable day when mom and dad would no longer be there. From this core group of parents, the movement in Charlotte began towards greater independence for retarded and disabled citizens.

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Former Special Olympics gold medalist Julie Rayburn is now employed as a helper-aid for mentally retarded children.

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The program these parents started depended on volunteers and a part-time director, who primarily provided day care for retarded children. The program evolved, however, into classroom training under contract with the Charlotte-Mecklenburg Schools. Several years later, the public school system opened its own classes for the educable mentally retarded students. At that point, the parents decided to turn their original program into a sheltered workshop and vocational training center, now called Nevins Center.

Nevins Center represents only one of the new opportunities that persons with a mental disability now have available to them. From attending regular classes in public schools to

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Nevins Center is the oldest sheltered workshop in the state.

receiving assistance from the Metrolina Independent Living Center, persons with mental or physical handicaps have more avenues available to them than ever before for living an independent life.

Confinement to a single family or to an institution is no longer the only or even the primary choice available to persons with a mental or physical handicap. Below is a sketch of some of the alternatives available in Charlotte.

**Sheltered Workshops.** Nevins Center, the oldest workshop in the state, provides work and vocational training to about 200 mentally retarded persons on an average day. Many of these persons also have physical handicaps, such as hearing impairments or orthopedic problems. Typically, a client comes to Nevins at the age of 18 after completing the public school program.

"When people first come here, we spend the first six weeks trying to determine what they *can do*", says Rick Dancy, director of Nevins. "Everybody has evaluated them from birth to find out what they *can't do*. We're not really interested in that. We are more interested in taking a success and building on it."

Clients go to the center Monday through Friday twelve months a year (except for two weeks' vacation at Christmas). The first four hours of the day are spent in work activity under contract with area businesses and industries. Typical jobs are building parts for phones, assembling washer and screw sets, packaging screws in bags, building wooden furniture, and making greeting cards. The last two hours are spent in recreation or in basic education classes.

Wages for their work depend on the clients' productivity. For example, if a business pays \$5 an hour to an employee who assembles 100 washer and screw sets each hour, it pays a Nevins client \$1.25 an hour if he only assembles 25 sets each hour.

According to Dancy, 85 percent of the clients at Nevins will never work in a competitive job environment. However, a person can work at

Nevins for years if he or she wants to, and many do. Presently, there is a six-month waiting list to get into the program at Nevins Center.

"For a lot of folks, if it weren't for getting up and coming over here each day, they wouldn't get up," says Dancy. "Others realize that if they're going to get a competitive job they are going to have to learn some skills."

Nevins is a private, non-profit organization with a 1984 budget of \$769,000. About half the budget comes from state and local government funds. The other half comes from private contributions and earned income from the products made at the workshop. The state Division of Mental Health, Mental Retardation, and Substance Abuse Services certifies the health and program standards at Nevins.

**Area Mental Health Authority.** Success at a sheltered workshop depends not only on developing job skills but on behavioral skills as well. If behavioral problems arise at Nevins, the client may go to a temporary program like the Adult Behavior Adjustment program at the county-operated Center for Human Development in Charlotte. Funded by state and local government, the center is part of the Mecklenburg County Area Mental Health Authority, one of 41 such programs that cover the entire state. These area programs offer a wide variety of services, primarily in community-based settings.

In 1981, the Adult Behavior Adjustment (ABA) program opened in Charlotte to help adults who were being dismissed from programs like Nevins—or who couldn't get accepted there as clients at all—because of behavioral problems. Some clients are easily upset and throw things or take another person's possessions, explains ABA director Janet Hince. Another person might continually leave the work area or refuse to cooperate with his supervisor.

"We reinforce desired behavior. This is our basic program. Reinforcement could be taking the client out to lunch or on a field trip. It could be praise or special attention," Hince says. "A lot of our clients only get social attention when they do what they are not supposed to do. As much as possible, we try to ignore that kind of behavior and reinforce positive behavior."

All clients at the ABA program are mentally retarded and are required to do certain tasks for which they receive reinforcement. "We are very goal oriented to seeing clients go on to less restrictive environments. This is a treatment environment, a behavior program for the entire six hours they are here each day," Hince says. "Some of our clients have never been in a program as an adult. ABA becomes an entry to other programs like Nevins."

**Developmental Day Program.** Until a decade ago, no alternative to family or institutional care existed for profoundly and severely retarded persons aged three and older. In 1973, St. Mark's Center opened. St. Mark's now serves more than 80 children and adults on a daily basis with a low three-to-one ratio of students to teachers. As a day school, St. Mark's concentrates first on developing a highly individualized curriculum for each student. Students might focus on developing gross or fine motor skills, self-care skills, or sensory skills. The school helps children and adults learn everything from brushing their own teeth to using playground equipment.

Older clients, or those who have progressed through the initial curriculum, might enter the Adult Developmental Activity Program (ADAP). Here students learn more advanced interpersonal and independent living skills. Students are exposed to recreational activities such as skating and swimming. Some may be able to learn vocational skills, which can lead to employment at a sheltered workshop. Local, state, and federal funds, along with private donations, support St. Mark's Center. St. Mark's works closely with other private and public groups, including the Nevins Center, the Association for Retarded Citizens, and local schools.

**Pre-Vocational Training.** In the last ten years, opportunities for handicapped persons have increased dramatically, from mainstreaming in public schools to community-based mental

health services and sheltered workshops. Before this increase in services, however, many handicapped persons did not have access to training that could help them get into a sheltered workshop or other job situation. And some persons are still missing out on the new programs. In Charlotte, a program called Project LEAR (Leisure, Education, and Recreation) helps such persons.

LEAR offers the only in-home, continuing education training for developmentally disabled persons in Charlotte. The LEAR clients are between the ages of 30 and 60, with an average age of about 40. LEAR staff conduct an in-depth questionnaire of incoming clients (or their parents or guardians). In 1982, of the 105 LEAR clients, 41 percent had received no special education, social services, vocational rehabilitation, or recreation programs—no community instruction or support services of any kind.

"When our clients were growing up, few special education services existed. Most of their parents basically lost hope," says Pat Keul, coordinator of Project LEAR. "There are not a lot of programs that work with the older adults. These people mostly show up on welfare roles, but most are ineligible for programs like Goodwill Industries or vocational services."

LEAR teaches independent living skills on a one-to-one basis in the client's home. The counselors also take clients on field trips to learn how to use public transportation skills, get along with others, handle money and personal grooming, and much more. LEAR estimates that 72 percent of its clients lack the skills to succeed in the work force or at a sheltered workshop.

Project LEAR, which has received federal funds and support from the University of North Carolina system, will soon merge with Goodwill Industries. The new program, to be called the Community Resources Training Project, will receive funding from the Charlotte/Mecklenburg Mental Health Authority and the United Way.

**Respite Care Homes.** Despite a growing number of programs in Charlotte to teach independent living skills, they all had one serious drawback until 1975. They were *day programs only*. There was no place where parents could leave their family member overnight in order to take a trip or just go out for the evening. In 1975, Respite Care Homes, under contract with the Area Mental Health Authority, began offering 24-hour overnight care for people with developmental disabilities or retardation.

Respite Care Homes places the client in a carefully screened, monitored, and state-approved household. The persons providing the care, usually parents themselves, are selected on

St. Mark's Center



the basis of their skills and sincere desire to care for the retarded or disabled client.

Funded by the county and state, Respite Care also charges fees based on a sliding income scale. One of its primary goals is to offer parents a periodic break or rest to reduce the possibility of institutionalization of their family member.

**Group Homes.** Institutions are no longer the only alternative outside the family for mentally retarded persons. For the person who gains the skills to live independently, group homes are an attractive option. Fifty mentally retarded persons currently live in 10 group homes in Mecklenburg County. There's a waiting list of 172 people for spots in the homes.

"There comes a time when just about all of us leave home. Why should the mentally retarded be any different?" asks Dancy, director of the Nevins Center sheltered workshop. Forty-six of the 50 persons living in the group homes in Charlotte come to Nevins Center every day, he says.

"The group homes serve as a place to live for the kinds of people who work in a sheltered workshop during the day," adds Dancy. This is one of the reasons that Nevins started planning in 1971 for a group home "community" on their own 45-acre campus. Ground breaking for the first home was in December 1983.

Nevins plans a total of nine group homes with six residents in each. Funding for the group homes came from grants from the City of Charlotte and the Kate B. Reynolds Health Care Trust of Winston-Salem.

"I'm a big believer in scattered house sites in the community. But I also believe that just like everybody else, mentally retarded persons should have the option to live in a neighborhood with other people like themselves," Dancy says.

One group home in a residential Charlotte community caused heated controversy when it was announced in May 1982. St. Mark's Center sponsored the house for five retarded persons on Windsor Drive. The first of the five residents moved into the house in July 1982 despite a series of community meetings and dissent from more than 70 area residents.

"It would be a shame for a person who had never been in a mental institution to end up in one," Dancy says. "But I'm not just interested in keeping them out of an institution. I'm interested in keeping them out of any inappropriate environment."

**Support Groups.** For adults with mental illness who may have been in and out of institutions for years and unable to live independently, the Mecklenburg County Mental Health Center sponsors a club called "New Directions." Max Nunez, director of New

Directions, says that it is called a club in order to get away from the idea that these people are sick or incompetent.

"Traditionally, these people have been treated as sick," says Nunez. "But the club takes away the aspect of sickness and lets them know that the club will work if they work." Each club member has duties and obligations to various committees on which they serve.

Since the beginning of New Directions in 1981, 80 members have joined to participate in every aspect of running the club—from kitchen and maintenance to clerical, research, and newsletter committees. Currently, the club meets one day a week but Nunez says the goal is to operate five days a week. He also hopes to find a house in the community for the club and move it away from the Mental Health Center to further break the connection to mental illness.

New Directions staff work with the members to help them find housing or employment. But members are responsible for running the club themselves. Staff will offer direction and assistance, but the work must be carried out by the client. "Basically, we involve people in normal functions of life. We put responsibility on the members. We let them know we expect them to do it, and most of them do," Nunez says. "They might have done nothing at home, but here they become productive." Most of the members have chronic schizophrenia and are referred from the mental health center or from local psychiatrists.

**Independent Living Center.** The U.S. Census reports 35,000 mobility-impaired persons in Mecklenburg County. Many of these physically disabled persons have no mental disability at all. In 1980, the Metrolina Independent Living Center (MILC) was founded to help primarily physically disabled persons live more independently. The Metrolina Center provides direct client services and works cooperatively with other city and community agencies. For example, the Metrolina Center helped start the Special Transportation Service, a van service run by the city of Charlotte which picks up disabled persons at their homes.

Rusty, a peer counselor for amputees at MILC, is a quadruple amputee from severe electrical shock. He came to MILC because he was bored. Unlike most disabled persons, Rusty was not working but had a fairly good income and needed something to do with his time. When he first came to MILC to volunteer, his wife was driving him everywhere.

"We asked him why he didn't drive himself," says John Ross, until recently MILC executive director. People like Rusty, who have lost both hands and both feet but still have some part of

their arms and legs, can be fitted to driving devices. "He had never thought for one minute that he might be able to drive," adds Ross. MILC put Rusty in touch with an expert who modifies cars and vans for handicapped persons. Now Rusty drives himself everywhere with the use of arm controls in a van with a wheelchair lift.

Another client, Jim, is a 44-year-old amputee who recently had a stroke. Jim's wife tried to lift him in and out of their mobile home but dropped him twice. They could not afford the ramp which would allow him in and out of his home.

A physical therapist who sees Jim three times a week contacted MILC. A staff member designed a ramp, then found a church to contribute the labor and materials and to build it. Another church widened Jim's bathroom door so he could wheel himself into the bathroom.

Ross says that, since MILC began, it has worked principally with housing assistance, housing modifications, and attendant care. MILC trains and certifies attendants and matches them with clients. In 1983, the legislature appropriated \$50,000 to MILC for the attendant care program as a pilot project for North Carolina.

Ross says that MILC has applied to the federal Department of Housing and Urban Development for a \$1 million loan to build a 40-unit apartment complex in Charlotte for

physically disabled persons. If approved, the complex would be the first in North Carolina for non-elderly disabled persons, according to Ross. The City Council has reserved a 33-acre site in the city for the housing complex, pending acceptance from HUD.

Most of the funding for MILC has come from the federal Vocational Rehabilitation Title 7 program, but that will end next year. After that, the agency hopes to become a member of United Way for a third of its \$650,000 operations budget. Another third would come from fundraising and the last third from fees for services.

**T**he Metrolina Independent Living Center, the Nevins Center sheltered workshop, the St. Mark's developmental day program, and other Charlotte programs are actively educating the public about the importance of independent living skills for citizens with disabilities. At the same time, they are helping persons with mental and physical handicaps learn to live more independently. People like Julie Rayburn would convince a wide range of people—from policymakers to neighborhood association members—of the value of these programs.

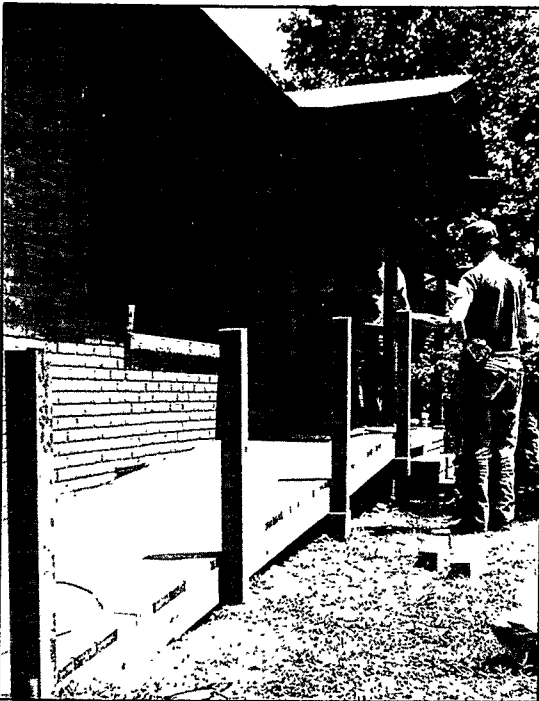
Julie, 34, is moderately retarded. In 1979, she was the first person from Charlotte to participate in the Special Olympics. She went to Rochester, New York, where she won a gold medal in the 50-yard dash and third place in the standing broad jump. She is now a volunteer helper at the Marion Diehl Recreation Center, a Charlotte Parks and Recreation project for the developmentally disabled. Her parents say the recreation program at Nevins' helped Julie develop her physical coordination to a higher level.

Julie's father, retired Presbyterian minister Robert W. Rayburn, is on the Nevins Center Board of Directors. He says of Nevins: "It's a through street. Before Nevins, there was only a dead end street."

This year, after working at Nevins Center for 11 years, Julie left. She accepted a job as a helper-aide at Ramsey Kindergarten, a private school for mentally retarded children. Even though Julie says she enjoyed working at Nevins, she is thrilled with her new job. "I love working there," Julie says. "When I got there, I was overwhelmed. There was lots of love."

Julie's parents, happy with Julie's new career as a kindergarten aide, also see what a difference their daughter makes for other people. "Parents [of the Ramsey students] are encouraged," says Julie's mother. "They see someone who is retarded working and contributing. It gives them hope." □

U. S. Navy Seabees volunteer to help the Metrolina Independent Living Center construct a ramp for a girl in a wheelchair.



Courtesy Metrolina Independent Living Center